

# Albinism in Zambia: information for children

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### Additional notes:

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Illustrations: [www.teresa-robertson.co.uk](http://www.teresa-robertson.co.uk)

# Living with Albinism in Zambia

## Information for children and young people



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# Why is my skin pale?

You have a condition called albinism which means you do not produce dark pigment (called melanin) in your hair, skin and eyes.



**In other ways you are just like others.**  
**Both boys and girls can have albinism.**  
**Albinism occurs in all countries around the world.**



***My parents both have dark skin.***

***Why is mine white?***

Albinism is inherited. Sometimes there is only one person in a family with albinism, sometimes there are more.



$A \blacksquare + \square a \quad a \blacksquare + \square A$



$a \square + \square a$

We all carry two copies of an inherited unit (called a gene) that produces pigment (melanin).

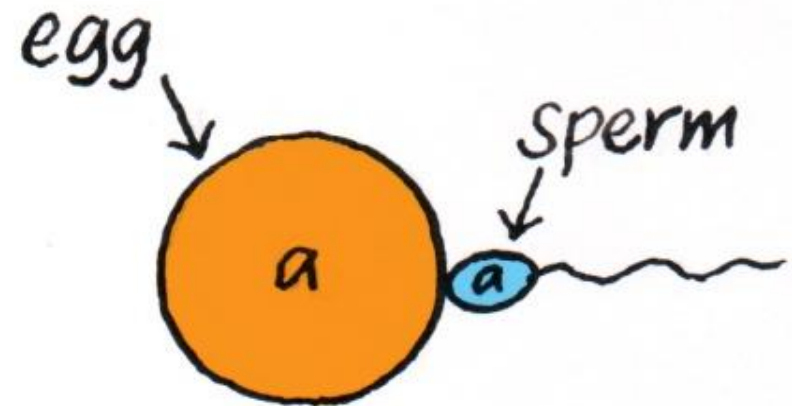
There are different forms of this gene: the **A** form produces melanin while the altered **a** form does not.

As you have albinism this means your parents are both carriers **Aa**; the **A** form is dominant and produces melanin (so they have dark skin, hair and eyes).

You have inherited the **a** form from both your mother and your father, so you do not produce pigment.

That is why you have albinism

Fertilization: **aa** resulting in a child with albinism.



In this case the sperm from the father and the egg from the mother both carry the altered form of the gene (**a**). When they join at fertilization the baby will be **aa** and will be born with albinism.

Albinism is a genetic condition that occurs at birth and lasts throughout life; it is not a sickness or disease and cannot be passed on through contact or touching.



## ***I have brothers and sisters who are black. How is this?***

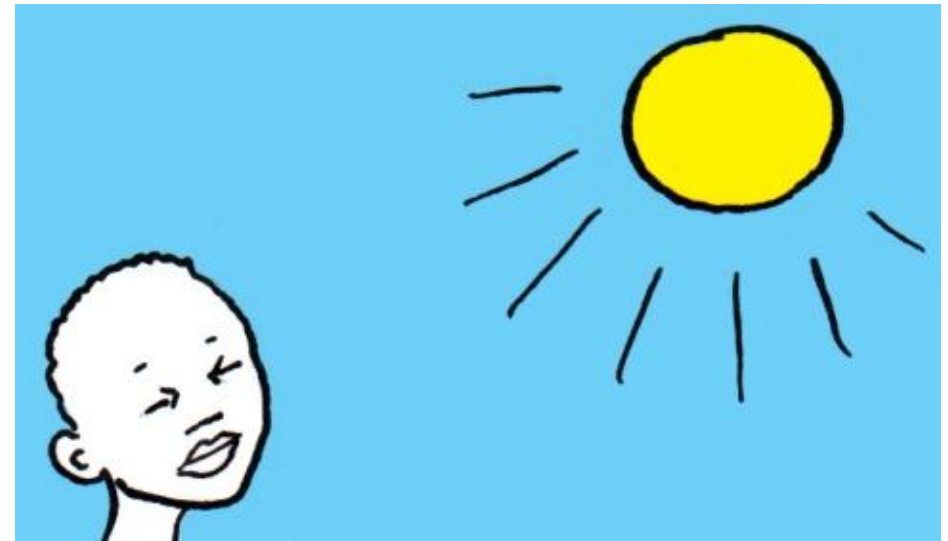
They have received at least one copy of the gene (A) that produces pigment. This could come from your mother, your father or from both your parents.



In this family two of the children have dark skin and two have albinism.

## ***Is my eyesight different from others?***

Yes, your eyes lack pigment and this changes the structure of your eyes. They 'wobble' from side to side which makes it difficult to see detail.

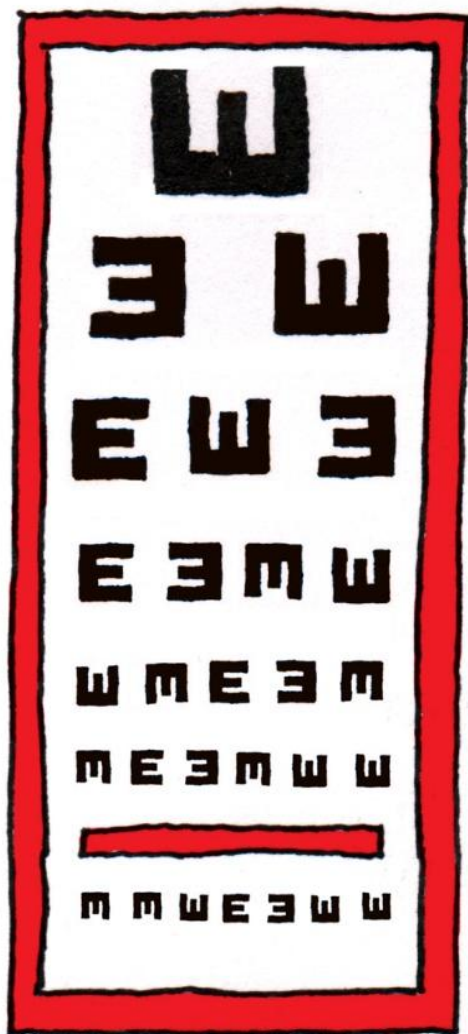


Your eyes are very sensitive to bright light.

## ***How does my eyesight differ?***

You will find it more difficult to see things at a distance. You may find it difficult to judge movement and speed, for example when a ball is thrown or a car is travelling towards you.

***My sister also has albinism but her eyesight is better than mine. Why is this?***



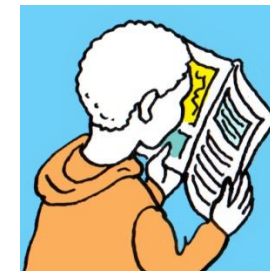
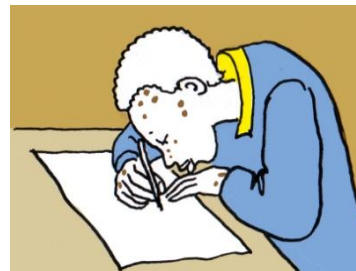
People with albinism all have reduced eyesight but this can vary from person to person, just like in people without albinism.

This is a picture of a chart used to measure your eye sight. If you have albinism you will have difficulty reading all these letters at a distance.

People with 'normal' vision can read these letters on the chart



***Will I go blind because I have albinism?***



No, your eyesight will change as you get older, but you will not lose your sight.

**Albinism causes low vision, not blindness.**

***Should I learn Braille?***

No. If you can see when you hold the book or object close to your eyes you do not need to be taught Braille.

***How can I manage with reduced/poor eyesight?***

Here are a few tips, which you probably know already:

- Use colour, shape or patterns to help identify and find objects

- Ask people to speak so you can recognize their voice and can follow lessons in class
- Do tasks like reading early, when you are fresh, rather than late in the day
- Some people with albinism find that their eyes 'wobble' less when they tilt their head.

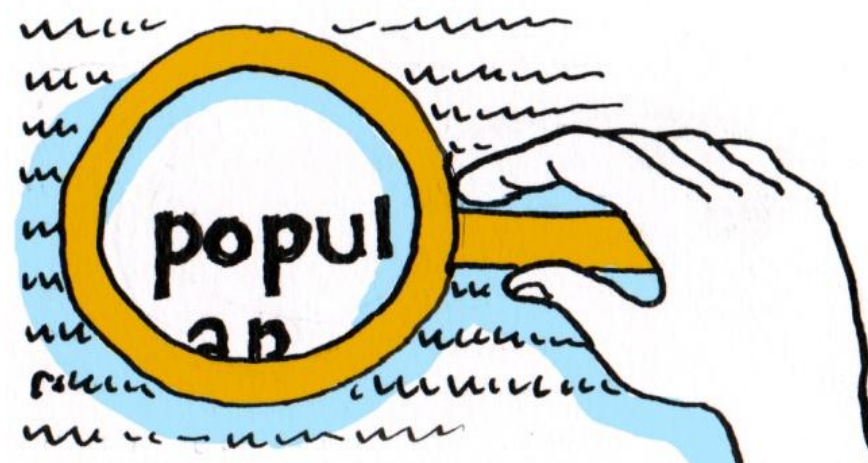


Virginia has albinism. When she started school she did not realize her friends could all see the board while she could not. She asked for help from her teachers and now she is a teacher herself.

## ***Is there anything that can help me see better?***

Prescription glasses can help you read.

Magnifiers that you hold in your hand will make letters and numbers larger. Donors may be able to provide these.



Remember the most important thing is how you use the vision you have!

## ***Why am I so sensitive to the sun?***

Having albinism means that you do not have black pigment that helps protect your skin and eyes from damage and discomfort caused by the sun's rays.

## ***How can I protect myself from the sun?***



- Wear a wide brimmed hat every day to protect your skin and eyes

- Wear long sleeved shirts and long trousers or skirts and sunglasses
- Choose dark, tightly woven material such as denim to give good protection from the sun
- When buying clothes hold them up to the light and choose ones you cannot see through
- Seek shade or remain indoors whenever possible, especially in the middle of the day

## ***Will I go dark if I stay in the sun?***

No. Your skin will go red, it will burn, blister and peel.

This can be painful so avoid the sun as much as you can.

**If you have wounds on your skin that do not heal, ask to go to the clinic or hospital.**

## ***How does the sun damage my skin?***

- UVA are ultra violet (UV) sun rays that age your skin
- UVB rays cause your skin to go red and burn
- Both damage your skin and cause sores.



## ***How does sunscreen help protect my skin from the sun?***

It contains ingredients that help protect your skin from the sun.

## ***How do I use sunscreen?***

- If affordable, use sunscreen that protects against UVA and UVB, with an SPF (sun protection factor) of at least 15, preferably 30
- Apply this to all parts of your skin not protected by your clothes, especially your face, neck and hands
- Apply to dry skin at least 15 minutes before going into the sun
- Apply more than once each day, especially after swimming or sweating
- Apply during the day; at night you can use any cream or Vaseline to soften your skin
- Even if you use sunscreen you should still wear clothes to protect your skin from the sun and try to avoid the sun during the middle of the day!

## ***When should I protect my skin from the sun?***



***Every day!***

***All year round!***

***Even on cloudy days!***

**Damaging UVA rays reflect off water, sand and concrete, and pass through glass.**

**This means your skin can burn if you are out on a river or lake, even if you are wearing a hat.**

## ***Is there any special food I should eat?***

No, you can eat the same food as everyone else in the family.



## ***I go red when I bath in hot water. Should I use cold water?***

No, the redness is temporary (it is not the same redness as you get when out in the sun!). You can use hot water to wash.

## ***How can my friends help me?***

- Join you playing in the shade or indoors rather than out in the sun
- Walk with you so that you are safe crossing the road and help you learn how to get around at school and in the community



- Call you by your name when they see you, so that you recognize their voice, even if you do not see them clearly
- Read out loud to you
- Help you copy notes from the board in school and share their notes with you afterwards.

## *How can my teachers help me?*



- Allow you to sit at the front of the class, in the middle so you can see the board
- Let you wear your hat indoors, to help protect your eyes from bright light
- Let you move to the board to see more clearly what is written
- Give you your own book to read, rather than sharing, so you can hold it close to your eyes

- Write in big, clear letters on the board and speak aloud while writing

- Provide tests and exams in large print
- Help you to avoid being in the sun as much as possible
- Give you indoor duties (and punishments if you have misbehaved!)
- Explain to other pupils what albinism is and why you are treated differently e.g. always sit at the front because you do not see as well as others.

**Show this booklet to your teacher!**

## *How can well-wishers help me?*

- Buy you a hat with a wide brim, long trousers or skirt or a shirt with long sleeves
- Buy you sunglasses
- Provide you with sunscreen lotion (although this is expensive and may not be freely available)
- Buy you a magnifier to make letters and numbers easier to see
- Tell others about albinism to help educate the community.



### *Plan your day -*

- Make sure you are wearing clothing to protect your skin and have your hat or umbrella before leaving home
- Do reading and learning earlier in the day when you are fresh rather than later when your eyes are tired
- Plan outdoor activities such as sport, gardening and farming for early in the morning or later in the evening when the sun's rays are not as strong
- Plan every day to try to avoid the sun and make sure your clothes cover as much of your skin as possible.



### *Does albinism give me special powers?*



**No, you have the same ability and potential as others.**



**Remember: *everyone has the right to a good education.***



## ***Where can I find out more about albinism?***

Families with a member who has albinism may want to join this organization which promotes the welfare of people with albinism in Zambia:

**Albino Foundation of Zambia**  
**Motto: Breaking the silence on albinism**



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